DOCUMENT RESUME

ED 258 130 CG 018 333

AUTHOR Gotay, Carolyn Cook
TITLE Needs for Psychosocial Support in Home Care Hospice Patients.
PUB DATE Aug 84
NOTE 12p.; Paper presented at the Annual Convention of the American Psychological Association (92nd, Toronto, Ontario, Canada, August 24-28, 1984). This research was supported by a grant from the Alberta Heritage Savings Trust Fund.
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Family Attitudes; *Individual Needs; *Patients
IDENTIFIERS Canada; *Caregivers; *Hospices

ABSTRACT

There is little research documenting the psychosocial support needs of hospice patients and their families. To assess hospice patients' and families' use of and perceptions of need for support, 77 patients and their families were interviewed during home care for terminal illness (Group 1), and 50 family members (84% spouses) were interviewed 1 year after the patient's death (Group 2). The interviews included questions related to physical and psychosocial functioning and service use. The results indicated respondents received and perceived a need for a variety of services, including nursing care, homemaking, physician home visits, and patient and family counseling. Perceptions of need were greater after the patient's death than during the home care period, suggesting that families often may not recognize or communicate their needs. Caregivers need to encourage self-reliance in patients and families while providing them with the support they require. (MCF)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED258130

Needs for Psychosocial Support in Home Care Hospice Patients

Carolyn Cook Gotay
Department of Community Health Sciences
The University of Calgary
Calgary, Alberta, Canada

BEST COPY AVAILABLE

CG 018333

Running head: NEEDS FOR CARE

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

X This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Carolyn Cook Gotay

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Abstract

Despite increased recent attention on developing programs of care for dying people, little documentation of the needs for psychosocial support as perceived by patients and families has been reported. This research presents data obtained through interviews with 127 families receiving care from a community-based palliative home care program. Results documented the variety of needs expressed, implying the necessity for co-ordinated care. Perceptions of needs were greater one year after a patient's death than during the time of home care, implying that families may often not recognize or communicate the needs that they are experiencing. Psychologists have important roles in addressing hospice patients' needs.

Needs for Psychosocial Support in Home Care Hospice Patients

In recent years, increased attention in health care has focused on the development of programs designed to provide specialized care for dying patients and their families. Such programs, often referred to as hospices, or palliative care services, attempt to give care when cure is not possible. Although these kinds of services may take a variety of organizational forms (e.g., home care, specialized units within hospitals, freestanding facilities; see Gotay, 1983), they are all oriented around several basic principles of care: seeing the patient and family as the unit of care; symptom control; support for families extending through the bereavement period; availability of services "on call" (cf: Cohen, 1979; Koff, 1980; Rossman, 1977; Stoddard, 1978). Such principles are derived from a concern about a wide variety of needs extending beyond the physical to the social, spiritual, and psychological domains. Meeting these needs requires an interdisciplinary approach to care, with psychologists in a position to play critical roles both in therapy (Klagsbrun, 1982; Liss-Levinson, 1982) and in research (Butterfield-Picard & Magno, 1982).

Little data documenting the need for psychosocial support from the perspectives of the patients and families themselves has been reported. A recent study by Rainey, Crane, Breslow, and Ganz (1984) found, in the 115 cancer

patients they surveyed, that 62% of them believed that they would be "very likely" or "somewhat likely" to use psychological counselling services from a hospice if they required hospice care; counseling was the third likeliest service to be cited, from a list of ten (coming after medical control of symptoms and home nursing care). Rainey et al.'s study provides valuable information to support the idea that patients, as well as program planners, accord priority to psychological needs. However, the participants in this study were responding from a hypothetical perspective, since none of them were currently receiving care from a hospice program, and only one in ten reported that they had considered enrolling in such a program.

What, then, are the perspectives of patients and families who have received, or are currently receiving, hospice care regarding their needs for psychosocial support? The objective of this study was to assess the use of and perceptions of need for support in patients and families under the care of a community-based hospice home care program, both during the time of terminal care and one year after the patient's death.

Method

The Hospice Program

The participants in this study were receiving care from

a service designed to provide comprehensive health care at home, enabling patients to remain in their own residences during terminal illness. The program was based in Calgary, Alberta, Canada, and it was designed to provide home care across this city of 600,000. The program operated out of the local board of health.

At the time of the study, the palliative home care service had been functioning for two to three years; its caseload was about 300 patients per year. The primary diagnosis of over 95% of patients was cancer, and about half were over the age of 65. To receive care from the program, patients required a medical referral, and during the average length of stay on the program of about two months, virtually all received nursing care, and many received homemaker support.

The Respondents

The respondents were 77 patients and their families assessed during the period of home care for terminal illness (Group 1) and 50 family members (84% of them spouses) assessed one year after a patient receiving care from the program had died (Group 2). All patients or families who had received care from the program for at least 14 days were asked to take part, and over 90% of those approached in both groups agreed to participate; one must note, however, that about one-third of the potential participants in Group 2 could not be located based on the program's information of one year earlier; the

mobility of bereaved persons has been noted by other researchers as well (Vachon, 1983).

Procedure

Data were collected through one-hour, semi-structured interviews conducted by trained female nurse-researchers in the patients' homes. The interviews included questions related to a number of areas of physical and psychosocial functioning, in addition to service utilization.

In this paper, we will focus on respondents' use of and their perception of their need for several services: nursing, homemaking, physician home visits, counselling for the patient, and counselling for the family. For each of these services, respondents were asked if they received help in this area. They were then asked, if they did not receive this form of assistance, whether they could use this help; if they did receive assistance, they were asked if more would be useful. Both groups were asked to respond in terms of their experience on home care: i.e., their present needs (Group 1) or their experience one year previously (Group 2).

Results

The findings can be seen in Table 1. First of all, it

Insert Table 1 about here

is clear that many patients require multiple kinds of assistance. This finding is particularly evident in Group 2's responses, where 46% or more people report receiving each kind of assistance.

Figures for receipt of care are probably higher in this group because respondents were answering in terms of the assistance they had received during the entire period of home care, whereas respondents in Group 1 were replying only based on the time that the patient had been receiving home care at the time of the interview, as little as 14 days. Additional needs often become apparent, and care delivered, as the length of terminal care increases.

It is interesting to note that perceptions of needs for additional assistance are greater for every kind of care after the patient's death, even though (in all cases except for homemaking) higher levels of care had been received by Group 2. It seems that one year later, families look back on their experience and see that they could have used extra help in many areas, whereas during the period of terminal care itself they are not as likely to identify their needs for assistance.

Conclusions

The multiple needs identified by home care hospice patients and families imply that psychosocial caregivers need to work closely with and coordinate their efforts with other care providers and agencies. The fact that perceptions of needs for assistance - psychosocial and other kinds of care - are greater after death occurs implies that caregivers should attend to needs that patients and families themselves may not express at the time near death. At that time, they may have too many

demands on their time to consider the ways in which they need help. Many families may also be reluctant to admit that they could benefit from assistance. Caregivers need to be sensitive to the ways that they can encourage self-reliance in patients and families, while at the same time providing them with the support they require.

Patients and families perceive themselves to have psychosocial needs during terminal illness and afterwards, many that they believe could be addressed more adequately. Psychologists have important roles to play in meeting these needs: through direct clinical services; through sensitizing and educating other members of the care team; and through developing programs and policies to provide for assessing and filling psychosocial needs of hospice programs.

References

Butterfield-Picard, H. & Magno, J.B. (1982). Hospice the adjective, not the noun: The future of a national priority. American Psychologist, 37, 1254-1259.

Cohen, K. (1979). Hospice: Prescription for terminal care. Germantown, MD: Aspen Systems Corp.

Gotay, C.C. (1983). Models of terminal care: A review of the research literature. Clinical and Investigative Medicine, 6, 131-141.

Klagsbrun, S.C. (1982). Ethics in hospice care. American Psychologist, 37, 1263-1265.

Koff, T.H. (1980). Hospice: A caring community. Cambridge MA: Winthrop.

Liss-Levinson, W.S. (1982). Reality perspectives for psychological services in a hospice program, American Psychologist, 37, 1266-1270.

Rainey, L.C., Crane, L.A., Breslow, D.M. & Ganz, P.A. (1984). Cancer patients' attitudes toward hospice services. CA - A Cancer Journal for Clinicians, 34, 191-201.

Rossman, P. (1977). Hospice: Creating new models of care for the terminally ill. New York: Association Press.

Vachon, M.L.S. (1983). Bereavement programs and interventions in palliative care. Progress in Clinical and Biological Research, 132E, 451-461.

Author Notes

This research was supported by a grant from the Alberta Heritage Savings Trust Fund: Applied Research-Cancer. This paper was presented at the American Psychological Association Convention, Toronto, Ontario, Canada, August, 1984.

I am grateful for the assistance of Donna Lentjes, Marja Verhoef, and Joyce Church in the conduct of this research.

This project was conducted while the author was at the University of Calgary. Reprint requests should be directed to Dr. C.C. Gotay, 41 Sierra Lane, Arnold, MD 21012.

Table 1

Assistance Received and Needed

Area of Assistance	Group 1 (n=77)		Group 2 (n=50)	
	Receives Help	Needs (More) Help	Received Help	Needed (More) Help
Nursing	100%	9%	100%	28%
Homemaking [a]	97%	21%	60%	32%
Physician Home Visit	16%	17%	60%	44%
Counselling - patient	23%	5%	48%	16%
Counselling - family	12%	4%	46%	24%

[a] Question posed in terms of patient receiving assistance for Group 1 and family member receiving assistance for Group 2.